BARRIERS TO HIV/AIDS TREATMENT AND TREATMENT ADHERENCE AMONG AFRICAN-AMERICAN ADULTS WITH DISADVANTAGED EDUCATION

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African Americans are disproportionately affected by acquired immunodeficiency syndrome (AIDS). New treatments that slow the progression of human immunodeficiency virus (HIV) infection offer hope for individuals living with HIV/AIDS, but lack of access to care and poor treatment adherence remain significant obstacles to HIV treatment. This study investigated the association between education literacy to HIV treatment adherence and barriers to care among African Americans living with HIV/AIDS. A community-recruited sample of 85 African-American men and 53 women receiving HIV treatment completed measures of health literacy, health status, treatment adherence, emotional well-being, and barriers to care. Nearly one-third (29%) of the participants had <12 years of education or were functionally illiterate, and those with low-education literacy were less likely to be adherent to HIV medications within the previous two days. Lower-education literacy also was related to reasons for missing medications and barriers to accessing medical care. Individuals of low-education literacy also were more emotionally distressed, lacked social support, and were less optimistic than those with higher education. These results indicate that education and health literacy are important factors in HIV-treatment adherence and access to medical care. Interventions are needed for improving treatment adherence among low-income minorities, and such interventions will need tailoring for individuals with limited reading ability. (J Natl Med Assoc. 1999;91:439-446.)

Key words: African Americans ◆ AIDS ◆ HIV

The acquired immunodeficiency syndrome (AIDS) crisis in North America continues to expand, particularly in urban areas among communities of color. In

the United States, 32% of men and 56% of women diagnosed with AIDS are African American.[1] Although there have been few significant breakthroughs in the fight against AIDS, advances in anti-human immunodeficiency virus (HIV) treatments have helped slow the progression of HIV infection, increased the life expectancy of individuals living with HIV/AIDS, and offered hope for controlling HIV infection as a chronic illness. Among the most promising anti-HIV therapies have been combinations of drugs that interfere with the enzymes necessary for HIV replication. Combining drugs that inhibit reverse transcriptase and protease enzymes are particularly effective because they suppress HIV at its initial and

later stages of replication.[2,3] The success of anti-HIV medications is, however, dependent on infected individuals accessing these drugs early in the HIV disease process and their ability to adhere to treatment regimens.

Combination anti-HIV medications are costly, and many individuals of lower socioeconomic levels have difficulty accessing care and often are unable to obtain quality medical care for chronic conditions, including HIV/AIDS.[4] Another essential factor in successful HIV treatment is adherence to medication regimens. Although combinations of anti-HIV therapies can effectively suppress HIV replication, inadequate dosing allows HIV to rapidly mutate and form new variants of the virus.[2] Even slight deviations in medication dosing and scheduling can cause a lapse in viral suppression, leading to genetic variants of HIV that can be resistant to an entire class of drugs, rendering some anti-HIV treatments ineffective.[5] Drug-resistant strains of HIV also are transmittable to others, creating an alarming threat to public health.[6,7]

Several factors influence HIV treatment adherence including forgetfulness, sleeping through a dose, traveling, adverse side effects, beliefs in the drug's effectiveness, and relationships with health-care providers.[8-12] Substance abuse, social support, and emotional distress also can reduce adherence to medical regimens, including anti-HIV therapies. Among demographic characteristics, race and ethnic background are commonly associated with treatment adherence. Studies of HIV treatment adherence report that African Americans are more likely to report poor treatment adherence than whites.[13] Similarly, Catz et al[14] found that minorities were more likely to miss clinic appointments than whites. Although ethnicity appears important in predicting HIV treatment adherence, the mechanisms that account for these differences are unknown.

The role of ethnic and racial background in treatment adherence may be related to the socioeconomic status of study participants, which in turn overlaps with lower education. The ability to read and comprehend medical instructions plays an important role in health, health care, and treatment adherence, especially among low-income populations. Baker et al[15] found patients of low-health literacy reported being in poorer health than patients of higher literacy. The authors also showed that health literacy was a stronger predictor of treatment adherence than years of education. In addition, studies show that poor functional health literacy impedes access to adequate health care.[16]

We recently examined the role of health literacy in adherence to anti-HIV treatments in a community sample of men and women living with HIV/AIDS. Health literacy was found to be more important in predicting HIV treatment adherence than substance abuse, depression, and attitudes toward health-care providers.[17] Our research, however, examined health literacy independent of years of education. Although literacy alone is important in treatment adherence and accessing health care, education is a more clinically useful index for patient management because determining education does not require specialized testing. Thus, the current study examined treatment-related issues in African Americans of low-education literacy living with HIV/AIDS. Low-education literacy was conceptualized as either having <12 years of education or scoring below an 80% correct response cut-off on a health-literacy test. Differences between individuals of low- and higher-education literacy were examined in terms of barriers to care, factors related to medication treatment nonadherence, and emotional well-being.

MATERIALS AND METHODS
Study Population
One hundred twenty-three African-American men and 82 African-American women who participated in a larger investigation of HIV-related health service utilization comprised the study population.[17] Because the current study focuses on medication adherence, 67 individuals who were not receiving anti-HIV therapies were omitted. The mean age of the remaining men and women who were receiving treatment was 39.7±7.5 years.

Participants completed three sets of measures in a single assessment session: assessment of health literacy; an interview to collect demographic characteristics, health status, current treatments for HIV/AIDS and treatment adherence, and factors related to treatment barriers and adherence; and self-administered measures of depression, emotional distress, optimism, and perceived social support (interview administered for persons who could not read).

Health Literacy. Health-related literacy was measured using an adaptation of the Test of Functional Health Literacy in Adults (TOFHLA).[18] This instrument formed the basis for defining literacy in the current study. The TOFHLA was developed as an assessment of health literacy in relation to health status and health-care access. Subjects were administered an adapted version of the reading comprehen-

sion section of the TOFHLA, selecting two of the three standard passages (instructions written for patients receiving an upper gastrointestinal series, and the patient rights and responsibilities section of a Medicaid application form), and adapting a third passage, matched for grade level and word frequency of target words that specifically addressed HIV/AIDS-related care. The scale included 53 four-option multiple choice items, in which sentences were completed by selecting the correct word from among the four options. For correct responses, scores ranged from 0 to 53.

Demographic Characteristics. Participants were asked their age, years of education completed, and their self-identified ethnicity and gender (for those who were transgender), and sexual orientation (gay, bisexual, or heterosexual).

Health Status. Because the study was conducted in a community-based service setting, biomedical data were collected through self-report measures. Participants were asked what month and year they had tested HIV positive, whether they had experienced 15 different HIV-related symptoms, and whether they had been diagnosed with AIDS case-defining conditions. Participants also provided their most recent CD4 cell count and viral load.

Treatment Status and Adherence. Participants were asked to identify their current HIV treatments and all doses taken in the previous two days. First, participants were asked to name the drugs they were taking. Next, interviewers asked participants to confirm the drugs they were taking by identifying their treatments among pictures of drugs shown on a chart. The interviewer then asked participants to recall the times they had taken each drug the day before. A daily calendar was used to help participants cue their memory and structure their responses. Interviewers recorded the number of doses taken for each drug. This section of the interview was repeated to collect the same information for the second day before the interview. Two-day treatment recall, for one and two days prior, formed the basis for calculating the proportion of prescribed doses using the following formula: total anti-HIV pills taken in past two days/total anti-HIV pills prescribed for past two days.

Participants also were asked to recall the times of missed dosage of their anti-HIV medications in the past 30 days. Participants marked the circumstances that played a role in their not taking medications during that time. This instrument assessed 14 rea-

sons for missing medications in the past 30 days, including forgetting to take a dose, not having medications on hand, being too busy, having too many medications to manage, feeling confused about dosing, medication side effects, sleeping through a dose, feeling depressed, and wanting to cleanse one's body. A calendar method was used to help participants who had missed medications in the past 30 days structure and recall events.

Perceived Barriers to Treatment. Participants were asked whether they had experienced 10 barriers to accessing medical care, including inability to pay for treatment, unsure of where to obtain care, lack of transportation, inconvenient clinic hours, having been treated poorly at a clinic, wanting to avoid being seen at a clinic, distrusting doctors, no longer caring about oneself, lack of child care, and being too drunk or high. Each experience was responded to as yes or no.

Depression. Participants completed the Beck Depression Inventory (BDI), a 21-item test that reflects cognitive, affective, behavioral, and somatic symptoms of depression. Questions are responded to along four levels of severity, scoring 0 to 3.[19] The BDI is a commonly used measure of depression that has shown reliability and validity, and was internally consistent in the current sample, $\alpha=.90$.

Emotional Distress. The 53-item Brief Symptom Inventory (BSI) was administered as an index of psychological distress and disturbances. The BSI includes items representing symptoms of somatic anxiety, obsessive-compulsive thoughts, depression, anxiety, hostility, paranoia, and psychoticism. The total score yields a General Severity Index, a reliable and valid measure of emotional distress with scores ranging from 53 to 265.[20]

Optimism. Optimism was assessed using the 20-item Beck Hopelessness Scale.[21] Items on this scale reflect both optimistic and pessimistic views of oneself and the future, including such items as "My future seems dark to me," "I look forward to the future with hope and enthusiasm," and "I have great faith in the future." This scale was reverse scored, with higher scores indicating greater optimism. The scale was internally consistent in the current sample, $\alpha=.90$.

Perceived Social Support. Perceived social support was assessed with a 15-item scale reflecting availability and quality of support. Example items include "There are several people I trust to help me solve problems," "If I were sick, I could easily find someone to help me with my daily chores," and "I

Table 1. Demographic Characteristics and Health Status of HIV-Positive African-American Men and Women of Low- and Higher-Education Literacy

	Low-Education Literacy (N=40)	Higher-Education Literacy (N=98)	
	No. (%)	No. (%)	P
Men	22 (55)	63 (64)	NS
Women	18 (45)	35 (36)	NS
Income <$10,000	35 (89)	62 (63)	.05
Identified as gay or bisexual	12 (31)	53 (54)	.05
Had been incarcerated	25 (63)	45 (46)	.1
History of injection drug use	14 (35)	25 (26)	NS
Nonadherent with HIV treatments	16 (40)	21 (22)	.05
Diagnosed with AIDS	28 (82)	72 (82)	NS
	Mean±SD	Mean±SD	P
Age (yr)	40.1±6.9	39.5±7.8	NS
No. HIV symptoms	6.1±3.2	5.5±3.4	NS
CD4 cell counts	310.2±222.2	370.0±222.1	NS
No. months tested positive	79.3±47.5	82.3±51.0	NS
Depression	15.4±10.5	9.4±7.9	.01
Generalized distress	114.3±39.2	90.7±31.3	.01
Optimism	2.9±.5	3.3±5.1	.01
Social support	2.8±.5	3.2±5.8	.05

HIV=human immunodeficiency virus; AIDS=acquired immunodeficiency syndrome; and NS=not significant.

feel a strong emotional bond with at least one person." Items were responded to on 4-point scales, with 1=definitely true and 4=definitely false; scores ranged from 15 to 60. The social support scale was reliable in the current sample, α=84.

Procedures

Participants were recruited from AIDS service organizations, health-care providers, social service agencies, community residences for people living with HIV/AIDS, and infectious disease clinics in Atlanta, GA. Details of the participant recruitment procedures are reported elsewhere.[7] Flyers announcing the study were posted and placed in waiting areas. Interested individuals phoned the research program to schedule an appointment to participate in the study. Participants completed informed consent in accordance with institutional review board guidelines, followed by literacy assessments, the health and treatment interview, and a self-administered survey. Participants who were unable to read the self-administered survey were interviewed to complete all study measures. The study took two to three hours to complete, and participants were compensated $50 for their time and participation.

Statistical Analysis

Groups were defined by education level; participants with <12 years of education were defined as low education, and based on literacy scores, participants who scored <80% on the health-literacy test were defined as low literacy regardless of their education level. Continuous measures are represented by means and standard deviations, using independent t tests to measure significant differences between education literacy groups. Categorical data are represented by percentages of low- and higher-education literacy groups, using chi-square contingency table analyses to measure significant differences. Finally, a multiple logistic regression analysis was conducted that predicted education literacy from variables that were significant in the univariate analyses.

RESULTS

Among the 85 men and 53 women receiving anti-HIV therapies, 19 (14%) had not completed 12 years

Table 2. Reasons for Having Missed Anti-HIV Medications in the Past Month Among HIV-Positive African-American Men and Women of Low- and Higher-Education Literacy

	No. (%) Lower-Education Literacy (N=20)	No. (%) Higher-Education Literacy (N=50)	P
Forgot to take dose	9 (45)	24 (48)	NS
Did not have the right medications	10 (50)	23 (46)	NS
Too busy doing other things	11 (55)	26 (52)	NS
Felt I had too many pills	6 (30)	7 (14)	NS
Got confused about medications	6 (30)	3 (6)	.01
Could not tolerate side effects	7 (35)	9 (18)	NS
Did not think it was helping	4 (20)	3 (6)	.1
Something unexpected came up	6 (30)	17 (34)	NS
Slept through a dose	12 (60)	16 (32)	.05
Felt depressed and overwhelmed	9 (45)	10 (20)	.05
Wanted to cleanse body	4 (20)	6 (12)	NS
Could not follow directions	5 (25)	8 (16)	NS
Too drunk or too high	3 (15)	4 (8)	NS
Traveling	3 (15)	13 (26)	NS

HIV=human immunodeficiency virus and NS=not significant.

of education and 21 (15%) demonstrated low literacy on the Test of Health Literacy for Adults. Thus, these 40 (29%) men and women were classified as lower-education literacy. The mean years of education were 10.5 ± 1.9 for the low education-literacy group compared with 13.6 ± 1.8 for the higher education-literacy group. In addition, the low-education literacy group scored an average of 73% correct on the health-literacy test compared with 96% correct for the higher-education literacy group. Table 1 shows the proportion of men and women with lower- and higher-education literacy. Participants of lower-education literacy were more likely to have annual incomes $<\$10,000$ (χ^2 [2, 137]; 10.17; $P<.05$) and less likely to be gay or bisexual (χ^2 [3, 137]; 6.16; $P<.05$).

Education Literacy and HIV Treatment Adherence

Forty percent of the participants of lower education-literacy levels missed at least one dose of their anti-HIV medications in the past two days compared with 22% of those with higher education (χ^2 [1, 138]; 4.99; $P<.05$). There were no differences in the number of medications or number of pills prescribed to the two groups ($P>.1$). Thus, poorer adherence in the lower education literacy group cannot be attributed to differences in dosing burden.

In addition, there were no differences in HIV-related health status between groups, suggesting that adherence differences were not accounted for by differences in disease progression (Table 1).

Twenty (50%) participants of lower education and 50 (48%) participants of higher education reported missing at least one dose of the anti-HIV medication in the previous 30 days. Participants of lower-education literacy were significantly more likely to miss medications because they were confused about what they were suppose to take (χ^2 [1, 70]; 7 34; $P<.01$), because they slept through a dose (χ^2 [1, 70]; 4.66; $P<.05$), or because they were depressed (χ^2 [1, 70]; 4.51; $P<.05$) (Table 2). Across groups, being too busy (53%), forgetting to take medications (47%), and sleeping through a dose (40%) were the most frequently endorsed reasons for missing medications, whereas beliefs about whether the drug was helping (10%), not wanting others to see the medications (10%), and being intoxicated (10%) were the least common reasons for missing anti-HIV medications.

Emotional Well-Being

Because depression was frequently indicated as a reason for missing medications among the participants in this sample, as well as the role of emotional health in treatment adherence literature, differ-
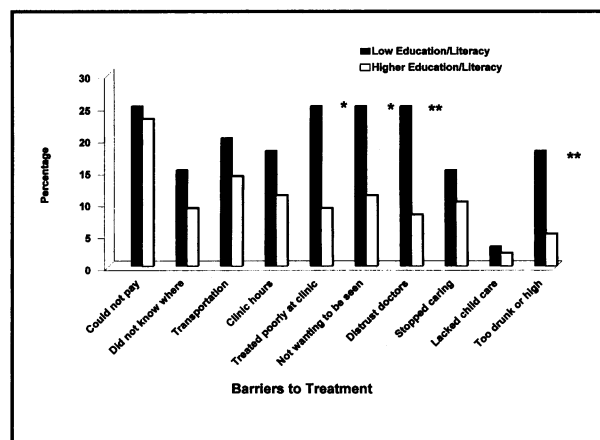
Figure 1. Percentage of individuals with HIV/AIDS of low- and higher-education literacy reporting barriers to accessing HIV/AIDS medical care (*P<.05, **P<.01).

ences between education literacy groups were examined on measures of emotional well-being and social support. Results showed that participants of lower-education literacy were significantly more depressed (t [128]=3.47; $P <.01$), more emotionally distressed (t [111]=3.28; $P <.01$), less optimistic (t [123]=3.48; $P <.01$), and perceived receiving less social support (t [128]=3.56; $P <.01$) compared with participants who had higher-education literacy (Table 1).

Barriers to HIV/AIDS Care

Figure 1 shows the percentage of participants of low- and higher-education literacy indicating barriers to receiving quality medical care. Participants of low-education literacy were more likely to have experienced problems accessing medical care because of treatment they received at a clinic (χ^2 [1, 137]; 5.86; $P<.01$), fear of being seen at a clinic (χ^2 [1,137]; 4.07; $P <.05$), lack of trust in providers (χ^2 [1,137; 6.96; $P <.01$), and being too intoxicated to seek treatment, (χ^2 [1,137]; 5.40; $P <.05$). Overall, inability to pay for services was the most frequent barrier to care (23%), while inaccessibility to child care was the least frequent (2%).

Multivariate Analysis

To examine the association between factors related to education literacy using a multivariate model, a multiple logistic regression analysis was conducted entering income, sexual orientation, scoring greater than moderate depression (>16) on the BDI, and

treatment adherence as predictors of education literacy. Because of the strong associations among the emotional well-being measures, depression was only included as an index of emotional well-being. Results revealed that income did not independently predict education literacy (odds ratio [OR]=2.7; 95% confidence interval [CI], .97-7.9). However, the other three factors did predict education literacy in the multivariate model: sexual orientation (OR=3.4; 95% CI, 1.3-8.9), depression (OR=4.1; 95% CI, 1.6-10.5), and treatment adherence (OR=2.6; 95% CI, 1-6.9). These findings therefore support most of the independent associations observed in the univariate tests.

DISCUSSION

The findings in this study should be considered in light of its limitations. Although a carefully constructed interview was used to collect medical and treatment adherence information, health status, medical diagnostic test results, or treatment were not verified using clinical records, laboratory tests, or other forms of external verification. We did not have access to clinical records and were unable to collect medical specimens because the sample was accrued from the community. In addition, we relied on self-report for mental health assessments. Although we used well-regarded clinical instruments, the potential bias in such assessments must be acknowledged. Finally, we did not assess neurocognitive functioning. Early symptoms of dementia may have influenced the responses of a small number of the participants and therefore should be considered a potential factor in the results.

Lapses in anti-HIV treatment adherence were high, with 27% of men and women missing at least one dose of their medications in the previous two days and 50% reporting nonadherence in the past month. Because treatment-resistant strains of HIV emerge after even a brief lapse in therapy, these rates of nonadherence are of grave concern. Although alarming rates of nonadherence were found in participants of both low and higher education and literacy levels, it is clear that interventions designed to improve HIV treatment adherence will require adjustments to accommodate individuals who experience difficulty reading and comprehending medical instructions. Participants of lower education and lower literacy who failed to adhere to treatments in the past month were more likely to report confusion about their medications than those with higher education and literacy.

Although our study design prohibits drawing causal conclusions, we believe that confusion over medications results from poor literacy. In addition, participants of low education and literacy were more likely to indicate two common factors in treatment nonadherence: sleeping through their medications and depression.[10,11] Participants of low education and low literacy also reported greater emotional distress and depression than those of higher education literacy, suggesting that integrating mental health services with primary medical care will benefit HIV treatment adherence.

Lower education and lower literacy were found to have associations with barriers to receiving HIV-related heath care, particularly because of how others perceived their treatment at a clinic, not wanting to be seen at a clinic, and distrust in doctors. One possible explanation for these findings is that providers do not adequately explain treatment options and related matters to patients who experience more difficulty understanding medical information. Alternatively, regardless of the time that providers spend with patients, individuals of poor literacy may attribute their difficulties understanding their treatments to the providers rather than to themselves. Another significant barrier to accessing care reported by low-education literacy participants was substance use. Given the prevalence of substance abuse in HIV-positive populations, it is not surprising that alcohol and drug use would interfere with access to care.[22] Substance abuse treatment therefore must be given priority in the comprehensive care to individuals living with HIV/AIDS.

CONCLUSION

Improvements to HIV treatment adherence are clearly needed for individuals living with HIV/AIDS. Unfortunately, materials that rely on reading, writing, or comprehension of verbal treatment instructions will likely fail for persons of low literacy. Improving adherence in this population will require instruction using pictorial guides and nonverbal, graphic directions. In addition, alarms and reminder systems can serve as prompts for taking medications and can prevent sleeping through medications. Individuals living with HIV/AIDS require multiple mental health, substance abuse, and social services. Providers of these services may serve as agents for improving health literacy and assisting patients to adhere to anti-HIV therapies.

Failure to improve adherence to anti-HIV treatments will seriously compromise the promise of treatment breakthroughs. The results of this study show that improving health literacy, or at minimum designing adherence assistance programs for people with limited literacy, must be included in HIV treatment initiatives.

Acknowledgments

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